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ABSTRACT

Educators, administrators, and service personnel who work with the developmentally disabled must define the aged developmentally disabled population. The term "developmental disability" refers to an individual with substantial developmental problems manifested during the first 22 years of life. Those who became disabled after age 22 are classified as a separate group; sub-classifications of these groups are necessary in order that adequate services be provided. Service providers in the fields of aging and developmental disabilities have traditionally paid little attention to the aging developmentally disabled individual. All aging individuals, whether or not developmentally disabled, must face the emotional needs of self-worth and integrity; the inevitability of death; and medical, vocational, educational, residential, and social needs. Differences between the developmentally and non-developmentally disabled aged suggest areas for service delivery concern, i.e.: (1) society's attitude toward differences; (2) behavior patterns of the disabled which maintain learned helplessness; and (3) difficulties in coping and dealing with death. (NRB)

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THE AGED AND AGING DEVELOPMENTALLY DISABLED: AN EXPLORATION INTO ISSUES AND POSSIBILITIES

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The Aged and Aging Developmentally Disabled: An Exploration Into Issues and Possibilities

An opportunity exists today for specialists in developmental disabilities and gerontology to work together on a common problem - the problem of living in the community which faces the aged developmentally disabled person. On the surface, it appears that there will be agreement on who this growing population is. However, this is not the case. Historically, knowledge of and services for the developmentally disabled have focused primarily on the needs of children and young adults. In recent years, however, attention has been extended to the older developmentally disabled person. One explanation for this recent attention by researchers and educators is the simple fact that with advanced medical technology people are living longer. This fact necessitates a caring society to explore and prepare for meeting the needs of people in old age, and those who face old age as developmentally disabled.

This paper will begin to focus on two of the many issues which face educators, policy-makers, and service providers who work with, or will work with, the developmentally disabled. The first part of the paper will examine the problem of defining the aged developmentally disabled population. The second part will examine some basic similarities and differences between the aged developmentally disabled and the non-developmentally disabled aged person.

The Problem of Definition

Richard Kalish (1977) has suggested five ways of defining when a person becomes old: 1) in terms of chronological age, 2) in terms of physical change, 3) in terms of behavioral change, 4) in terms of social roles, and

5) in terms of self-report. Since the passage of Social Security legislation in 1935, the focus has been on the chronological criteria as the most formal definition. Gerontologists continue to debate the usefulness and functionality of this classification. However, it seems agreeable that our legislation has formally defined "old age". The issue becomes convoluted when we begin to examine developmental disabilities. Developmental disability is an administrative designation used by federal government to refer to an individual with substantial developmental problems manifested furing the first twenty-two years of life. Prior to the change in the DD legislation in 1978, a developmentally disabled person was defined as an individual with mental retardation, cerebral palsy, epilepsy, autism or syslexia manifested during the developmental period prior to age eighteen. The recent change in the federal legislation has muddied the waters concerning who will be considered developmentally disabled under the law. However, one thing is clear about this group of developmentally disabled elderly people. They do not include individuals who become disabled after age twenty-two. The handicapped elderly are seen as a different population group.

For purposes of clarification, perhaps it would be useful to define the elderly (individuals over sixty-five years of age) as follows:

1. The normal elderly;
2. The disabled elderly (individuals disabled after age 22);
3. The developmentally disabled elderly (individuals disabled prior to age 22).

If federal legislation changes, these groups will continue to be redefined. However, it seems that certain sub-classifications of these three primary groups will become necessary if we are to adequately serve these people. (Dickerson, 1974.)

Another important definitional problem relates to whether the aged developmentally disabled person can be classified as part of the "frail elderly" designation. The severely and profoundly handicapped would easily fit into the "frail" designation regardless of age at onset of the disability. However, if the designation "frail elderly" only refers to individuals who are over seventy-five years of age, the developmentally disabled aged might not fit into the designation since they tend to have shorter life spans than the non-developmentally disabled aged. Thus, the age demarcation of frail elderly may need to shift when we are talking about the developmentally disabled elderly. (Rowitz, 1979.)

Neither the service providers in the aging field or in the developmental disabilities field have paid much attention to the aging and aged developmentally disabled individual. Dickerson and her colleagues at the University of Michigan (1974) have labeled the mentally retarded aged as "invisible people". They are not mentioned very much in either the gerontology literature or the developmental disabilities literature prior to the last few years. The aged developmentally disabled person is in double jeopardy. Not only does this individual face the problems of the aged, but he also faces the problems of the "mentally impaired". If we superimpose on this double jeopardy problem that most developmentally disabled aged are also poor, we have a triple jeopardy problem (Sweeney, 1980).

It becomes increasingly clear that this population is not easily defined, thus, providing services to a population not clearly definable becomes problematic, if not impossible. In the State of New Jersey, for example, we are perhaps speaking of a small percentage of the total developmentally disabled population, about 2%, but this accounts for a Statewide total of over 100,000 developmentally disabled people over the age of sixty-five (D.D. Council, 1980).

Nationwide figures show an increasing number of developmentally disabled people living longer, and living alone, without support systems. This minority population is in need of special kinds of services from both the aging network and the D.D. network.

Dickerson (1974), in one of the only major investigations on the DD aged, conducted at the University of Michigan, pointed to a number of important questions which need answering if we are to begin to serve the aging and aged developmentally disabled. Among her many questions were:

1. Do the developmentally disabled tend to age more quickly than the normal population?

2. Are there similarities between the aging processes of the developmentally disabled and the mentally ill?

3. To what degree is the aging process of the developmentally disabled more pronounced because they have not learned personal and social skills at younger ages?

4. Why have so few surveys been undertaken to carry our case findings regarding the identification of the aged DD in the community, although surveys have been undertaken on younger DD persons?

5. Why are the DD not prepared for community living during all stages of the life cycle?

6. Why do the aged DD seem to skip the "middle age" phase of development and move from a prolonged adolescence into the phase of being old?

7. What are the best alternatives to institutionalization for the aged DD? How do the selection of residential options differ by level of severity of disorder?

These questions are similar for both the aged and the developmentally disabled network, and we have heard them all before. Since 1974, attempts have been made to investigate both quantitatively and qualitatively these questions. Yet cooperative efforts between the two service networks are

often frustrated by federal and state mandates and limited funding. The recent curtailment of state funding for work-activity centers in New Jersey is a prime example.

The second major point of exploration I would like to examine is our awareness to some of the similarities and differences of the aged developmentally disabled versus the aged non-developmentally disabled.

Overall, the developmentally disabled and the non-developmentally disabled have more similarities than differences in all aspects of their lives. Foremost, they are individuals first, developmentally disabled second. They are individuals with their own uniqueness and individual personalities. Perhaps this quality makes them more like us than different; however, for years it has been quite the opposite. Whether one is developmentally disabled or not, an overriding similarity is the reality that as one grows older one must recognize the finality of one's existence. Death is a stage of the life cycle through which we will all pass, developmentally disabled or not. We will all face the emotional needs of self-worth and integrity as we grow older in a society which continues to value youth and energy, and seemingly discourages the same energy and desire to be productive in its aged. Similarities between the aged person and the aged developmentally disabled person are also visible with respec to medical, vocational, educational, residential needs and social needs in general. The aging process has no barriers, the process of physical deterioration of our bodies will affect, in varying degrees, all aging bodies, developmentally disabled or not.

Another similarity common in the life cycle of all aging individuals is

the fear resulting from the social isolation as family members, friends and companions die.

The differences between these two populations, aged developmentally disabled and aged non-developmentally disabled, are visible to varying degrees, and indicate areas for service delivery which will enhance the quality of life for all its members (Carelli, 1979).

I will limit my exploration to three basic differences.

1. Society's Attitude toward Differences

Many in society do not allow or accept differences, exemplified in such labels as "abnormal" and "deviant". We have yet to truly adopt the stance which titles a paper - "Differences Are Not Defects". Rather we have degrees of acceptances or priorities for differences. For example, intelligence has a low priority for acceptance, while mobility and speech problems may have a higher priority. Aging developmentally disabled have been victims of this "spoiled identity" since birth.

2. Maintaining of a sense of helplessness - learned helplessness, passivity and submission

Patterns of behavior which reflect passivity and a sense of helplessness by the institutionalized developmentally disabled is a recognized problem. This problem is related to prolonged inactivity and rewarded submissiveness. The environment which created this personality plays a role in creating and maintaining dependency. Life experiences have included arrangements that work against the development of personality and independence and have the effect of dooming the developmentally disabled to a deteriorating lifetime in this institutional mode.

Even for the non-institutionalized, the home environment is often dominated by others "doing for" the developmentally disabled, a situation which contributes to learned helplessness. Often the developmentally disabled have been treated as invalids long before any medical problems necessitate such care, encouraging overcomplaining in a few cases, but more often general poor self image and little assertiveness. Their dignity as individuals is further affected by their needs for privacy and affection not being met in many cases. These individuals easily become prey for exploitation.

3. Dealing with Death

One important issue for all aging and aged is dealing with sorrow, grief and bereavement as the number of family members, friends and acquaintances diminish through death as the life cycle is played out. The non-developmentally disabled most likely have experiences with death from which to draw coping abilities. The developmentally disabled have been denied opportunities to deal with death. They have not been exposed to death and included in the preparations and customary expressions of sorrow, grief and respect. For those developmentally disabled who are institutionalized, experiences of friends and staff leaving the institution might be similar to the death experience. They are denied the opportunities to deal with this ultimate life experience.

In an excerpt from a soon to be released book "Living to be Old", the author quotes a Swiss author, "I have come to the conclusion that there is one essential profound underlying problem, and it is that the old are not loved". The author, Ronald Blythe, refers to a common experience of all aged, "This is one thing all elderly feel - unloved - feel they are an obligation/duty and not loved". This is clearly a similarity for the aged developmentally

disabled and aged non-developmentally disabled. However, the developmentally disabled have always felt unloved throughout life. This is the greatest challenge to us.

There are other similarities and differences. I've chosen these to encourage you to challenge your experiences, knowledge, skills and attitudes for exploring and identifying others.

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